



DataInsights



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Health Status Assessment Project -- Year One Report

The Health Status Assessment Project is a three-year survey which will allow the Managed Risk Medical Insurance Board (MRMIB) to evaluate the health status of children newly enrolling in the Healthy Families Program and changes to health status over time for children who remain enrolled in the HFP. The project examines the physical and psychosocial benefits of having access to comprehensive health, dental and vision insurance.

MRMIB established a special committee to consider options for assessing health status, including the population to survey, the instrument to be used, and how to measure changes in health status over time. The PedsQL™ 4.0 (Pediatric Quality of Life Inventory™ Version 4.0) was selected by the Healthy Families Program Quality Improvement Work Group to measure parent and child perception of the child's *health related quality of life*. The survey measures physical and psychosocial health functioning of the child. The Health Status Assessment Project is being conducted in partnership with researchers at the Center for Child Health Outcomes, Children's Hospital and Health Center, San Diego.

Project Funding

The David and Lucile Packard Foundation provided \$320,000 for this three-year project. Funds are being used for survey administration and analysis. MRMIB provides in-kind staff support to the project.

Survey Design

Changes in the health status of HFP subscribers are being measured by surveying a sample group of subscribers during their first month of enrollment

and again after their first and second years of enrollment. The study is being conducted by mailing the PedsQL™ 4.0 questionnaire to subscribers during their first month of enrollment in one of five languages (English, Spanish, Vietnamese, Korean, or Chinese) based on the language of the applicant. The questionnaire was mailed to approximately 20,000 subscribers who enrolled in the program during February and March of 2001. The returned questionnaires were compiled and analyzed to develop a baseline measurement of health status. The questionnaire will be mailed to the same group of subscribers during their one-year and two-year anniversary month in the program. The data collected after the second and third round of surveys will be compared with the baseline data to measure changes in health status.

Survey Measures

Demographic variables examined in this study include age, gender, language, ethnicity and the presence of a chronic health condition. In addition to demographic variables, the relationship between a subscriber's use of services (e.g., presence of a regular source of care, routine medical visits, office visits, emergency room visits, overnight hospitalizations, problems getting care) and health status is examined.

PedsQL™ (Pediatric Quality of Life Inventory™) Outcome Measure

The health-related quality of life outcome measure is the PedsQL™ 4.0 Generic Core Scales. The PedsQL™ 4.0 Generic Core Scales include child self-report for ages 5-18

and parent proxy-report for ages 2-18, and measure the core health dimensions (physical, psychological, social functioning) as delineated by the World Health Organization, as well as role (school) functioning. The PedsQL™ 4.0 Generic Core Scales have been shown to distinguish healthy children and pediatric patients with acute or chronic health conditions, and are related to indicators of morbidity and illness burden.

Previous research and evaluation projects with the PedsQL™ 4.0 have demonstrated a consistent difference between healthy children and children with chronic health conditions such as asthma, arthritis, cancer, diabetes, and cardiac conditions (Varni, Seid, & Kurtin, 2001; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2001). Healthy children have been shown to have significantly higher PedsQL™ 4.0 scores than children with chronic health conditions.

The PedsQL™ 4.0 has also been shown to be responsive to interventions of known efficacy, to be sensitive to different levels of disease severity, and to have an impact on clinical decision making for pediatric chronic health conditions (Varni, Seid, Knight, Uzark, & Szer, in press). Higher PedsQL™ 4.0 scores have also been shown to be positively related to parent report of their children's health care quality.

Design and Calculation of the PedsQL™ 4.0 Generic Core Scales Outcome Measure

The PedsQL™ 4.0 questionnaire encompasses four Scales: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning (5 items). The PedsQL™ 4.0 questionnaires are comprised of parallel child self-report and parent proxy-report formats. Child self-reports are administered to young children (ages 5-7), children (ages 8-12), and adolescents (ages 13-18) years. Parent proxy-reports are administered to parents of children ages 2-4 (toddler), 5-7 (young child), 8-12 (child), and 13-18 (adolescent). The parent proxy-report forms are parallel to the child self-report

forms, and are designed to assess the parent's perceptions of their child's health related quality of life. The items for each of the forms are essentially identical, differing only in developmentally appropriate language or first or third person tense.

The survey instructions ask how much of a problem each item has been during the past one month. A 5-point response scale is utilized (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Higher scores indicate better health related quality of life. To create the Total Scale Score (all 23 items), the mean is computed as the sum of the item responses divided by the number of items answered in the Physical, Emotional, Social, and School Functioning sub-scales. To create the Psychosocial Health Summary Score (15 items), the mean is computed as the sum of the item responses divided by the number of items answered in the Emotional, Social, and School Functioning sub-scales.

Sample

Packets containing both child self-report and parent proxy report questionnaires were mailed to 20,031 families.

A total of 10,241 families (51%) returned the questionnaires. Of those returned, 10,067 parents completed the PedsQL™ 4.0 parent questionnaire and additional survey items and 5,972 children completed the PedsQL™ 4.0 child questionnaire. There were more parent proxy-reports than child self-reports, because children ages 2-5 were not given a questionnaire to complete. In some cases, a child self-report was returned without a corresponding parent proxy-report, or a parent proxy-report was returned without a corresponding child self-report.

Table 1 presents the sample characteristics by age, language, and ethnicity.

Table 1.
Sample Counts and Response Rates by Age, Language and Ethnicity

	Returned	Response Rate	% of Sample
AGE			
Toddler (2-4)	3124	59%	30.5%
Young Child (5-9)	2491	48%	24.3%
Child (8-12)	3214	50%	31.4%
Adolescent (13-16)	1412	47%	13.8%
LANGUAGE*			
English	4399	44%	43.0%
Spanish	5193	58%	50.7%
Chinese	333	58%	3.3%
Korean	171	55%	1.7%
Vietnamese	145	56%	1.4%
ETHNICITY			
White/non-Latino	1407	46%	13.7%
Latino	6299	53%	61.5%
African American	240	37%	2.3%
Asian/Pacific Islander	1204	54%	11.8%
Native American	41	46%	0.4%
Not Reported	1050	50%	10.3%

* Note: Language refers to language of questionnaire.



Key Findings:

- ✓ The ethnicity, language, age, and gender distribution of the sample matches those of the overall Healthy Families Program (HFP) population.
- ✓ African American and White parents were *less* likely to complete the survey, and Latino and Asian/Pacific Islanders parents were significantly *more* likely to complete the survey.
- ✓ English survey respondents were less likely to complete the survey and Spanish survey respondents were more likely to complete the survey.

Results

Overall Scores

Table 2 presents the total number of responses received for each item, the mean and standard deviation of the PedsQL™ 4.0 scale scores for child self-report ages 5-18 and parent proxy-report for ages 2-18 for the total sample.

Prior research shows a score of 83 is what healthy children, on average, score on the PedsQL™ 4.0 survey instrument.

If a child's score falls one standard deviation below the mean, monitoring and possible medical intervention should be considered, while scores two standard deviations below the mean require immediate medical intervention. Eighteen percent (1,949) of the sample children fell within one standard deviation below the mean, while four percent (454) fell within two standard deviations below the mean.

Table 2. PedsQL™ 4.0 Scores Child Self-Report and Parent Proxy-Report

Scale	Number of Responses Received	Mean	SD
Child Self-Report			
Total Score	5,972	82.76	13.22
Physical Health	5,962	86.86	13.88
Psychosocial Health	5,964	80.57	14.76
Emotional	5,967	78.04	18.73
Social Functioning	5,951	83.89	17.52
School Functioning	5,909	79.75	17.00
Parent Proxy			
Total Score	10,066	81.38	15.90
Physical Health	10,050	83.26	19.98
Psychosocial Health	10,067	80.25	15.82
Emotional	10,044	80.28	16.99
Social Functioning	10,036	82.15	20.08
School Functioning	8,466	76.91	20.16

Note: Although a total of 5,972 children and 10,067 parents completed the PedsQL, for some subjects there were not enough subscale items completed (e.g., greater than 50% of the number of items in the subscale) to generate a score. For example, 17 parents did not complete more than 4 of the 8 items in the Physical Health subscale, so a score could not be computed (10,067 - 17 = 10,050). It should also be noted that the lower number for the School Functioning subscale largely reflects instances where the child was not attending school within the previous 30 days (e.g., summer vacation), so the items were not completed.

High standard deviations are explained through the basic construction of scores. Given the range of scores (0=never, 25=almost never, 50=sometimes, 75=often, 100=almost always), slight variations in perception can generate large deviations in points generated.

Scores by Selected Demographic Variables

Table 3 contains a summary analysis, delineated by selected member characteristics (age, gender, language, and ethnicity).

Table 3. Summary PedsQL™ 4.0 Scoring by Selected Demographics.		
Category	Score	
	Mean	SD
GENDER		
Male	81.26	15.88
Female	81.48	15.92
AGE		
Toddler	87.47	12.44
Young Child	78.05	16.44
Child	78.88	16.60
Adolescent	79.48	16.38
LANGUAGE*		
Spanish	79.23	17.12
English	83.49	14.18
Chinese	83.22	13.91
Korean	82.88	15.82
Vietnamese	87.35	15.57
ETHNICITY		
White/non-Latino	84.53	13.40
Latino	80.44	16.45
African American	82.90	13.63
Asian/Pacific Islander	82.32	15.70
Native American	83.75	15.79
Not Reported	81.17	15.77

We examined the influence of demographic variables on PedsQL™ 4.0 scores. There was a slight correlation between age and parent proxy-report PedsQL™ 4.0 scores, such that parents of older children tended to view them as having slightly lower health related quality of life.

Comparing scores among language groups, parents responding in Spanish report significantly lower PedsQL™ 4.0 scores for their children than do parents responding in English, Korean, and Chinese, who in turn report lower scores than parents responding in Vietnamese.



Key Findings:

- ✓ Children enrolled in the Healthy Families Program have experienced health related quality of life similar to the general child population.
- ✓ Comparing four racial/ethnic groups (White, African American, Latino, and Asian/Pacific Islander) reveals that children of White parents had significantly higher health related quality of life than children of Latino parents, with children of African American and Asian/Pacific Islanders falling in between.

Associations between chronic conditions and perceived Health Related Quality of Life

Table 4 contains the PedsQL™ 4.0 scores for healthy children and children with a chronic health condition in the sample. As shown, 8.7 percent of the sample subscribers surveyed indicated a chronic condition. Children with a chronic health condition were identified as having one of the following conditions; Asthma, Attention Deficit Hyperactivity Disorder (ADHD) or Depression.

Table 4. PedsQL™ 4.0 Scores - Parent Proxy Report: Children with and without a chronic condition				
Scale	Without a chronic condition		With a chronic health condition	
Parent Proxy	N	Mean	N	Mean
Total Score	8709	82.32	831	73.18
Physical Health	8696	84.08	830	76.99
Psychosocial Health	8711	81.27	830	71.08
Emotional	8692	81.20	829	71.08
Social Functioning	8690	83.05	824	75.06
School Functioning	7287	78.27	756	65.58



Key Findings:

- ✓ Children without a chronic health condition report significantly higher Health Related Quality of Life than children with a chronic health condition, with the largest variance experienced in school functioning.
- ✓ Rankings by scale are the same for both chronic and healthy conditions. In general the highest scores, regardless of condition are for physical health with the lowest in school functioning.

Associations between access and utilization of care and Health Related Quality of Life

Associations between process variables (access and use of services) and health related quality of life (PedsQL™ scores) were examined. Two process variables were associated to the child's health related quality of life:

- 1) Parent reports of instances during the past 12 months when they had problems **getting care for their child that they or a physician felt was necessary** ("In the last 12 months, how much of a problem, if any, was it to get care for your child that you or a doctor believed necessary?")
- 2) Parent reports of instances during the past 12 months when they felt their **child should get medical care but didn't** ("In the past 12 months, has there been any time when you thought your child should get medical care, but did not?").

Table 5. PedsQL™ 4.0 Generic Core Scores Problems getting necessary care for the child in the year prior to enrolling in HFP				
	No Problems		Yes Problems	
Scale	N	Mean	N	Mean
Total Score	7664	82.67	2044	76.65
Physical Health	7650	84.43	2042	79.05
Psychosocial	7669	81.62	2042	75.27
Emotional	7648	81.59	2039	75.05
Social Functioning	7647	83.48	2036	77.53
School	6405	78.38	1751	71.74

Table 5 shows PedsQL™ 4.0 parent proxy-report scores for children experiencing problems **getting care** versus those who did get care in the 12 months prior to enrolling in the HFP.

Table 6 shows PedsQL™ 4.0 parent proxy-report scores for children whose parents **thought they should get medical care, but did not** versus those who did get care in the 12 months prior to enrolling in the HFP.

Table 6. PedsQL™ 4.0 Generic Core Scores Received care vs. did not receive care when parent thought necessary in the year prior to enrolling in the Healthy Families Program				
	Received Care		Did Not Receive Care	
Scale	N	Mean	N	Mean
Parent Proxy				
Total Score	8,144	82.60	1,783	76.08
Physical Health	8,126	84.34	1,785	78.59
Psychosocial	8,145	81.56	1,784	74.62
Emotional	8,123	81.63	1,781	74.12
Social Functioning	8,120	83.40	1,779	76.98
School	6,797	78.20	1,556	71.52

Comparison of children with or without chronic health conditions

Table 7 compares the number and percentage of subscribers reporting problems getting care by whether the family reports a chronic condition.

Table 7. PedsQL™ 4.0 Generic Core Scores Problems getting care – with and without a chronic health condition		
Category	No problem getting care	Yes problem getting care
Without a Chronic Health Condition		
Number in Sample	6,839	1,644
Percent of Sample	81%	19%
With a Chronic Health Condition		
Number in Sample	513	316
Percent of Sample	62%	38%

Table 8 describes subscribers reporting instances during the past 12 months where they felt their child *should have gotten medical care but did not* by children with and without a chronic health condition samples.

Table 8. PedsQL™ 4.0 Generic Core Scores: Felt child should have received care but did not Children with and without a chronic health condition		
Category	No problem getting care	Yes problem getting care
Without a chronic health condition		
Number in Sample	7,281	1,437
Percent of Sample	84%	16%
With a chronic health condition		
Number in Sample	572	263
Percent of Sample	69%	31%



Key Findings:

- ✓ In the 12 months prior to enrolling in the HFP, approximately 20 percent of families reported problems *getting necessary care* for their child.
- ✓ In the 12 months prior to enrolling in the HFP, approximately 18 percent of families reported that the child did not receive care when the parent thought it was necessary.
- ✓ In the 12 months prior to enrolling in the HFP, comparing chronic versus healthy populations, families report it is twice as likely to have problems getting care and receiving care if their child had a chronic condition.
- ✓ The health related quality of life of those children whose parents report access barriers was significantly less than that of children who did not face these access barriers.

Summary of Year One

The first year of this three-year survey has been successful in establishing a foundation for studying the Healthy Families Program's impact on subscriber's health status. Highlights of the first year include the following:

Was the first year survey successful?

Over 10,000, (51%) of subscribers surveyed, participated in this initial round. No telephone follow-up or incentives were used to promote participation. This number is important in two ways. First it demonstrates the willingness of the Healthy Families Program subscribers to participate in efforts to improve the program. Secondly, it represents the largest sample of its kind in the study of health related quality of life utilizing the PedsQL™ survey instrument.

What is the overall health profile of the Healthy Families Program Population?

The health profile of children enrolled in the Healthy Families Program, as measured through the PedsQL™ 4.0, showed no significant differences to children in the general population.

Approximately 9 percent of the subscribers surveyed indicated their child had a chronic condition identified as asthma, ADHD or depression. This observation is important because these children experience significantly lower health related quality of life along all five dimensions (physical, psychosocial, emotional, social functioning and school functioning), than children who were not reported to have a chronic health condition.

White and English survey respondents report significantly higher overall scores than Latino and Spanish survey respondents, with Asian/Pacific Islander and African American respondents having scores in-between.

Do barriers to access and utilization have any impact on the overall health status of the Healthy Families Program population?

There is a correlation between the ability of subscribers to access care and their overall health related quality of life. In the year prior to enrolling in the HFP, approximately 20 percent of the families identified a problem in receiving needed care for their child. Children identified with a chronic condition were twice as likely to experience an access problem.

Years two and three of project

Years two and three of the study have been funded and will follow the original sample through the second and third year of their enrollment in the Healthy Families Program. Scores for years two and three will be compared to this initial year to determine if enrollment in the program has changed the health related quality of life of the Healthy Families Program subscribers.

REFERENCES

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